

By Peter DelNero and Alexandra McGregor

From patients to partners

When we started graduate school 5 years ago, we were determined to learn everything we could about cancer. We spent all our time in the lab developing an arsenal of experimental techniques. However, in our daily work with petri dishes and microscopes, we felt that something was missing. We learned all about tumor biology, but we knew very little about the human dimensions of cancer. Even though our research is far from the clinic, we believed that interacting with patients and survivors would improve our understanding of cancer and the quality of our science.

With permission from our advisers, we contacted the director of a local cancer center to find out whether he might be interested in working with us. He was enthusiastic about connecting scientists-in-training with the cancer community; in fact, he was already discussing this idea with another group at our university. Together, we started hosting monthly seminars where researchers and patients interact and learn from each other. Some months, a graduate student gives a lay-language presentation about an important aspect of cancer research. Other months, community members describe their experiences of living with cancer. We also organize informal activities that promote patient-researcher dialogue, such as lab tours, book clubs, and participation in cancer support groups. One lung cancer survivor even spent a summer conducting experiments with us. Our relationship with the cancer center has created a continuous stream of new opportunities.

The partnership with the patient community has deeply influenced our formation as scientists. Our conversations have revealed gaps in our knowledge, exposed biases and assumptions, and even opened new paths for inquiry. We have learned about the hidden costs of cancer and the day-to-day obstacles patients face with their work, health insurance, family life, and plans for the future. By speaking with cancer patients, we have also learned to exercise openness, empathy, and reflective listening. Over time, we have fostered special relationships with patients and family members, and many have become our closest friends. Occasionally, we come face-to-face with the devastating reality that current treatments are not good enough.

The patient-researcher partnership transformed our research from an intellectual exercise into a deeply personal



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evolved into a formal curriculum for public engagement in cancer research. This aspect of our work became a highlight of our graduate experience.

Through our partnership, we discovered that research is not the only way that scientists can make a positive difference in the fight against cancer. Outside the lab, we can nurture personal relationships with individual patients, survivors, and families. Researchers are well placed to disseminate information, dispel common misconceptions, and share the scientific process with the cancer community. Most importantly, we can be good, supportive listeners. As we pursue the next phase in our research careers, we know that our patient involvement will continue. For us, it has become an integral part of what it means to be a cancer scientist. ■

Peter DelNero and Alexandra McGregor are doctoral students at Cornell University. They gratefully acknowledge Bob Riter, Robert Weiss, and all the community members and students who have been involved in the partnership.

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